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The challenges and opportunities in researching intimacy and sexuality in care homes accommodating older people: a feasibility study.

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ORIGINAL RESEARCH: EMPIRICAL RESEARCH –
QUALITATIVEThe challenges and opportunities in researching intimacy and
sexuality in care homes accommodating older people: a feasibility
study

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M. (2017) The challenges and opportunities in researching intimacy and sexuality
in care homes accommodating older people: a feasibility study. *Journal of
Advanced Nursing* 73(1), 127–137. doi: 10.1111/jan.13080**Abstract****Aim.** To explore the challenges of conducting research on sexuality and intimacy
among older care home residents.**Background.** Sexuality and intimacy are neglected in care policies and practices.**Design.** Qualitative analytical study drawing on poststructuralist theorizing.**Methods.** Semi-structured interviews were conducted with residents and spouses
($n = 6$) and care staff ($n = 16$) in two care homes in Northwest England in 2014.
The sample was obtained through a network of 'research-ready' care homes.
Thematic analysis was used to make sense of narratives with the aid of NVivo10.**Results.** Participant responses highlight the workings of ageist erotophobic
discourse that undergirds the assumption of residents (and old people generally)
as postsexual. This materialized in reservations about the research ranging from
opposition on moral grounds to doubts about its feasibility given the age-group
concerned. However, residents and care home staff can also draw on counter-
discourses that resist/challenge ageist erotophobic thinking, which materialized in
methodological and ethical recommendations.**Conclusion.** Participants generally agreed with the principle of the research and
made recommendations that could counter/resist ageist erotophobic governance
and guide researchers on sampling, style of questioning and communicating with
(prospective) study participants on a sensitive subject.**Keywords:** care, dementia, nursing, nursing home care, older people, patient
participation, sexuality

Why is this study needed? This study is needed because it highlights:

- Details of varying responses by stakeholders (residents, their significant others, care home staff, service providers/funders and policy makers) to a complex, sensitive and neglected issue that concerns human rights, for example, to self-expression;
- how ageist erotophobia contributes to the denial and marginalization of residents' sexuality and intimacy needs;
- aspects of good practice that could inform research concerning sexuality and intimacy in care settings for older people in countries with more developed welfare systems and liberalizing attitudes to sex, intimacy and sexuality.

What are the study's key findings?

- Ageist erotophobic discourse can encourage the assumption of older care home residents as postsexual but some residents and staff can draw on counter-discourses that resist/challenge such thinking.
- While there are likely to be some moral reservations about researching sexuality and intimacy in aged care facilities, these could be eclipsed by support for such research, especially among care staff having to deal with complex dilemmas.
- Study participants made recommendations about researching intimacy and sexuality in aged care facilities concerning the need to sample widely and for sensitive styles of questioning and communicating with (prospective) study participants.

How should the findings be used to influence policy/practice/research/education?

- Highlight the importance of investigating intimacy and sexuality in care settings for older people with a view to extending holistic provision and meeting rights to privacy, freedom of association and avoidance of inhumane treatment.
- Inform researchers and stakeholders of key difficulties in researching and meeting needs concerning sexuality and intimacy in care settings for older people.
- Highlight the value of consulting a seldom-heard group on a sensitive subject and provide ideas to help challenge stereotypes of residents and older people as prudish and postsexual.

Introduction

Attempts by older people to express sexuality and intimacy are often ridiculed (Simpson *et al.* 2015). Birthday cards for older citizens reveal the casual, widely legitimated nature of

ageism (Bytheway 1995). Stereotypically, older people are viewed as prudish and beyond sex (Mahieu *et al.* 2014). Internationally, scholarship has neglected sex, sexuality and intimacy in later life (Gott 2005, Doll 2012, Villar *et al.* 2014). Such pervasive silences reinforce older people's and care home residents' exclusion from the sexual/intimate imaginary and reveal more about cultural anxieties over ageing sexuality than individuals' wishes, feelings and desires (Simpson *et al.* 2015).

Investigating intimacy and sexuality in aged care settings is important for various reasons. Related demographic and social changes since the latter part of the twentieth century have resulted in increased longevity and the likelihood of re-partnering (Sassler 2010). Besides, opportunities for sexual/intimate self-expression might be more restricted following transition into aged care (Doll 2012, Bauer *et al.* 2014, Villar *et al.* 2014), although desiring and needing intimacy do not cease with age (DeLamater *et al.* 2008, Gott 2005, Kuhn 2002). Despite 25 years of 'community care' legislation in the UK, which emphasizes the personalization of support services (Department of Health 2007), older people's sexuality and intimacy needs appear designed out of health and social care policy, systems and practices (Hafford-Letchfield 2008).

Using poststructuralist methodology, this article addresses the value of consulting key stakeholders that is, residents, their significant others and care home staff on researching sexuality and intimacy. This issue concerns whether to do any such research and how anyone should go about such an enterprise. On the basis of themes identified in interviews with residents and spouses and focus groups of care home staff ($n = 22$) in 2014, we discuss the workings of ageist erotophobia (Simpson *et al.* 2015). We deploy this concept to reflect anxieties concerning older people as sexual beings, which can result in constraints on their sexuality (sometimes self-imposed) by defining them as beyond sexuality or what we term 'postsexual'. However, we also illuminate counter-narratives that indicate resistances/challenge to ageist erotophobia and residents' and care staff's recommendations concerning inclusivity. These forms of thought and practical recommendations figure as part of ethical and methodological practice in researching a sensitive issue with seldom-heard groups. Given the relative paucity of literature on the topic in question (Bauer *et al.* 2012), our findings could resonate beyond their local and national contexts. They could be instructive for fellow academics and professionals based in countries with developed welfare systems and liberalizing attitudes towards sex, intimacy and sexual difference.

Background: demographics and scholarship

The issue of intimacy in care homes for older people is important when we consider that of the 10.3 million people aged 65 or over in the UK, more than half a million individuals (around 5% of this population subset) are accommodated in a 'communal home' (Office of National Statistics (ONS) 2014). This figure includes older people living in shared accommodation. It is also noteworthy that the sub-sector of care accommodating older people in the UK is largely privatized with 70% (350,000) of the 500,000 beds being situated in for-profit homes (Laing 2014). Further, individuals aged 85 or over represent 58% of the older care home population (ONS 2014) with nearly 1:10 men and 1:5 women aged 85 or over living in such circumstances (ONS 2011b). Female residents outnumber males by nearly 3:1 (Office for National Statistics 2014) and approximately two-thirds of care home residents experience some form of dementia (Office for National Statistics 2011). This profile is not dissimilar to other countries with developed welfare systems like Australia. In this case, 57% of residents are aged 85 years or over, 70% of all permanent residents are female and 52% of all residents have a dementia (Australian Institute of Health and Welfare (AIHW) 2012).

The literature relating to intimacy and sexuality in aged care facilities appears limited but is growing. While its main theme concerns the marginalization of ageing sexuality and intimacy, it also recommends interventions that recognize multiple, intersecting forms of exclusion (Hafford-Letchfield 2008) and offers some education and training resources (Bauer *et al.* 2014). Our recent review of the literature on sexuality and intimacy in care homes (Simpson *et al.* 2015) revealed a body of work that is largely Australian or North American. This work notes that while sexual appetite can decline because of a confluence of biological (health-related), psychological (mental health, adaptation to ageing) relationship-related and social reasons (e.g. ethnicity, gender socialization), sexual enjoyment remains significant in later life (DeLamater *et al.* 2008). One article advises professionals against assuming that ageing and dementia diminish the importance of sexuality (Deacon *et al.* 2006). Further, there remains a significant strand of sexological, genitocentric thinking concerned with who is still engaged in heterosexual penetrative sex to orgasm in physically changed circumstances (Gott 2005). An article by Trudel *et al.* (2000) typifies this heteronormative, book-keeping approach that keeps figures on sexual activities but ignores older people's capacities as adaptive sexual/intimate and emotional agents (Mahieu *et al.* 2014).

In the context of care homes, when not considered too private or personal (Bauer 1999), sexuality and intimacy were seen as irrelevant to ageing identities and citizenship (Gott 2005, Hafford-Letchfield 2008, Doll 2012, Bauer *et al.* 2014, Villar *et al.* 2014). Also, sex, sexuality and intimacy appear eclipsed by concern in the gerontology literature with maintaining biological and psychological functioning (Bauer 1999). While such factors are important (see DeLamater *et al.* 2008), the exclusion of intimacy/sexuality falls short of a holistic approach to meeting needs.

If residents identifying/identifiable as heterosexual are understood as postsexual, the situation appears further complicated for older lesbian, gay bisexual and trans (LGB&T) individuals whose distinct care needs are even more neglected or else made problematic (Willis *et al.* 2013). Approaches to delivering equality in care settings in English-speaking countries, professing to 'treat them all the same', commonly entail presupposition of heterosexuality (National Council for Palliative Care and the Consortium of Lesbian, Gay, Bisexual and Transgendered Voluntary and Community Organizations 2012, Phillips & Marks 2008, Westwood 2015, Willis *et al.* 2016). Indeed, the choice can be stark. LGB&T residents can either risk victimization by carers and fellow residents or hide their hard-won identities and thus endure self-denial, constant self-policing and isolation. (Almack *et al.* 2010, Witten 2014). While the various reports mentioned above have focused attention on issues of equality and diversity, they too have neglected older LGB&T people as sexual/intimate beings (Simpson *et al.* 2015).

As intimated, a more critically focused, sociologically informed body of work is emerging that is concerned with causal complexity, diversity, equality and rights and has addressed sexuality and intimacy needs. In the USA, the biopsychosocial model of aged sexuality has been applied to the study of ageing sexuality and addresses the 'interplay of body, mind and social context' in this process (DeLamater & Moorman 2007: 922). Some of this more critical work is alive to the discursive and structural impediments to addressing sex, sexuality and intimacy needs in care homes for older people, which should be considered part of a holistic enterprise. For instance, in the UK, Hafford-Letchfield (2008) provokes thought about how to manage or overcome impediments to meeting sexuality and intimacy needs. This work highlights the need for training for care home staff to address the combined/intersecting effects of ingrained ageism, sexism and homophobia and transphobia. Further, Dyer and das Nair's (2013) systematic review identifies obstacles experienced by professionals in addressing service user sexuality/intimacy, particularly in relation to age, learning

difficulty and ethnic and sexual differences. In a Catalanian/Spanish context, research by Villar *et al.* (2014, 2015) is distinct for having sought the views of residents themselves and care staff and has avoided using testimony of the latter as a proxy for the views/experiences of the former. In Australia, Bauer *et al.* (2014) have developed a resource to help care home staff facilitate older residents' sexuality and intimacy needs that could be adapted to other national contexts. Furthermore, research on older Australia women has given voice to their expressed need for information on sex and recognition as sexual beings (Fileborn *et al.* 2015).

The study

Aims and research questions

This study aimed to consult care home residents, spouses and care home staff on two related research questions:

- What are the key issues involved in researching sexuality and intimacy (with a view to supporting resident choices)?
- If residents, significant others and care home staff consider it feasible and worthwhile, how should any study of sexuality/intimacy be designed and conducted?

Design

This feasibility study was designed to consult residents, their significant others and care staff/homes on the principle of conducting research on sexuality and intimacy. Convenience sampling and participant recruitment strategies reflected a need for pragmatism given that approximately two-thirds of residents experience some degree of dementia (Office for National Statistics 2011). Data collection was based on semi-structured interviews with residents and non-resident spouses and focus group discussions with care workers to access a range of perspectives. Poststructuralist methodology, which concerns how we see the constitution of our social worlds (ontology) and how we know/make sense of them (epistemology), assumes that we see and understand the world through discourses (Wright 2004). These refer to narratives that regulate thought and behaviour often unconsciously and in ways that secure compliance with certain social ideals (Wright 2004). However, such a methodology allows of agency given that individuals (as part of social groups) can develop counter-narratives that challenge/unsettle orthodoxies (Arribas-Ayllon & Walkerdine 2008). Such an approach was combined with thematic analysis to analyse participant accounts.

Recruitment

The fieldwork was conducted between May–August 2014 in care homes owned by two private providers known to the research team: care home one (CH1) a medium-sized home for up to 65 residents; and care home two (CH2) accommodating over 100 residents. Both homes, located in urban areas of Northwest England, were involved in a network of 'research-ready' homes – the Care Homes Research Group (CHRG). CHRG consists of private, public and voluntary sector homes that are attuned to and/or have experience in participating in research. It is maintained by NHS staff. Managers in care home 1 (CH1), approached a range of staff who they considered to have the appropriate expertise to form a focus group. No residents currently accommodated in the home had sufficient capacity to consent to be involved in the study. The care home did, however, identify two (non-resident) female spouses of residents and the former agreed to take part in the study as interviewees. In care home 2, (CH2), managers identified residents with capacity to consent (one of whom was interviewed with his spouse) and convened a group of staff to form a focus group. A plain-English participant information sheet (PIS) was provided to enable prospective participants to make an informed decision about whether to take part.

Participants

Three residents participated in the study: one male and one female resident, both in their early eighties (CH1) and one male resident in his early sixties (CH2). Three non-resident female spouses of male residents were also interviewed and two of these participants (CH1) provided insight into accounts of dementia and intimacy. The other spousal participant was interviewed with her husband in CH2. One spouse was in her early 60s, another aged 50–65 and the third spouse, an older woman, did not volunteer an age-bracket. All residents and spouses identified as white British

Table 1 Interview respondent characteristics: three residents and three spouses.

Gender	
Male	2
Female	4
Age	
60–70	3
80+	2
Not given	1
Status	
Resident	3
Spouse	3

Table 2 Focus group participant characteristics ($N = 16$): gender, age, status and ethnicity.

Gender	
Male	2 (13%)
Female	14 (88%)
Age	
18-30*	5 (31%)
31-49	7 (44%)
50+	4 (25%)
Status	
Direct care staff**	9 (56%)
Managerial/nursing (& dementia)	5 (31%)
Administrative	2 (13%)
Ethnicity	
White British	15 (94%)
Other	1 (6%)

*Connotes young adulthood and other age-groups represent middle-age and later career stage participants.

**To represent non-managerial care staff contributing directly to everyday care and having significant contact with/knowledge of residents.

and had worked in occupations that would locate them as working-class economically and culturally.

Sixteen staff were interviewed in two focus groups (CH1-FG1 = 9 and CH2-FG2 = 7). In FG1, (CH1), care home staff participants comprised two Registered Nurses educated to degree level, two managers and five care assistants ranging in age from their twenties to their early sixties. FG2 comprised care assistants, a Registered Nurse, a receptionist and a non-managerial administrator who ranged in age from the early twenties to early fifties. Each group involved staff with specific expertise in dementia care. Only one participant identified as other than 'white British' and two participants were male (FG1). The characteristics of interviewees and focus groups participants are presented in Tables 1 and 2. These characteristics are discussed in the Findings section.

Data collection

Semi-structured interviews were used with residents and spouses because they lend coherence to the encounter and can reveal unanticipated themes and respondent perspectives (Maxwell 1996). Focus groups were used with care home staff as an economical way of accessing a range of opinions through debate in situ. They represent a dialogic method that can afford participants a higher degree of control over the content of discussion and encourage creative thinking about and solutions to collective concerns (Frankland *et al.* 2001). The questions used both in interviews and focus groups asked participants to imagine various forms of intimacy (same- and opposite-sex) in a fictitious care home (supported

by suitable images e.g. of couples holding hands). Participants were shown vignettes alongside questions of difficulties that the characters might face (see Figure 1 below) but they were asked to discuss the use of this method or any other methods and the need for our proposed research.

Ethical considerations

Ethical approval was obtained from the Social Care Research Ethics Committee (SCREC reference: 14/IEC08/09), which falls under the aegis of the Health Research Authority (allied to the National Health Service). Due to the sensitivity of the subject, interviews were gender-matched with vignette-style questions, which were designed to maintain focus on the principle of addressing sexuality/intimacy rather than details of sexual histories, which participants could regret disclosing. Following SCREC recommendations, a distress protocol was developed, which offered guidance to interviewers in the event of upset among study participants. All names mentioned in the analysis are pseudonyms and we have attempted to recognize the innate dignity of participants in our analysis of their views, which involves critical engagement rather than criticism of such views and recognition of their reflexive capacities.

Data analysis

Interviews and focus groups were audio-recorded, transcribed verbatim and the data uploaded into NVivo10 qualitative analysis software to organize data coding and cross-referencing. Initially, open coding was used that consisted of identifying simple descriptive codes/instances such as: 'intimacy and sexuality discourses'; 'dementia and sexuality/intimacy'; 'enabling sexuality/intimacy' and 'how to ask questions'. Secondly, such instances were grouped into broader themes, that is: 'ageist erotophobia' (involving constraints on sexuality); 'resistance to ageist erotophobia' and 'recommended approaches/research methods'. Thirdly, the broader categories were distinguished into sub-themes (or subcodes within larger codes) such as: 'types of resistance' (whether by staff or residents); 'dementia' was subdivided into 'constraints' and 'recommendations avoiding governance'. The 'methods' category was subdivided into: 'sampling strategies'; 'ethical practices' (that covered including individuals with dementia) and 'communication styles' (including questions to ask or avoid). Three members of the research team independently read the transcripts and assigned initial codes inductively through engagement with participant narratives (involving three 'passes' through the dataset). Consensus on a coding frame was negotiated in

Researching sexuality/intimacy: vignette 1

Let's imagine a married couple, say, Jim in his late 70s and Dorothy in her early 80s (like the accompanying image) are living in Pine Trees care home. With this in mind:

- what kind of problems if any might the couple face in maintaining a sexual relationship?
- Who could help the couple if they wanted to continue with sex/intimacy and in what ways?
- What problems if any might the couple might face if unmarried?

Figure 1 Researching sexuality/intimacy vignette.

the research team and final themes were then compared with the narratives of each participant and agreed by the research team. Thematic analysis (Braun & Clarke 2006), was used to make sense of participant accounts. This method focuses on identifying and interpreting latent themes in participants' accounts. Consistent with poststructuralist methodology, this analytical approach recognizes the socially constructed character of narratives (Braun & Clarke 2006) that is, that stories are created via involvement in relations of power and everyday interaction and are used to make sense of experiences.

Rigour and trustworthiness

The research instruments, vignettes and images of intimacy were agreed by the research team and in consultation with two representatives from older people's organizations, which included a LGB&T group. Interim findings found support from a consultative conference on sexuality and intimacy in care homes that involved 50 participants including care home staff, healthcare academics and representatives from the public and voluntary sectors. As Lewis and Nicholls (2013) have argued, such a strategy can extend understanding of how stakeholders understand their experience of delivering and receiving a service. While we make no claims to generalize from a small sample, as Kvale (1996) has argued, accounts produced through qualitative methods, which draw on common ways of thinking, could be *indicative* of stories retailed/heard in similar situations and resonate beyond the immediate (and regional and national) context of the study.

Findings

Analysis of participant accounts generated three main themes: the effects of ageist erotophobia; forms of resistance/challenge to such thinking; and the need to ensure inclusivity and sensitivity in researching sexuality and

intimacy. Before, we discuss these themes, we provide an explanation below of the two sub-samples – interviewees and focus groups.

The above sub-sample is not wholly representative of the care sector for older people where the average age on admission to care home is 85 (Office for National Statistics 2011), which indicates that those needing to live in care homes are commonly among the most physically frail and dependent. These individuals may be more inclined to see themselves as postsexual or simply be less able to engage in sexual activity (DeLamater & Sill 2005). However, the sub-sample reflects that the care sector accommodates some 'younger old' people with life-limiting conditions. Together with the limited number of older residents with capacity to consent, the modestly sized sub-sample was also attributable to the time-limited nature of the funding for the study (three months).

The sub-sample of staff reflects the spread of roles likely to be encountered in care homes and that care staff are more likely to be female and middle-aged (Hussein 2009). Nearly two-thirds of focus group participants were aged over 30. However, the sub-sample differs markedly from the national profile of care staff in terms of ethnicity. Ethnic 'minority' communities are considerably under-represented here given that they account for around a fifth of care sector employees and often in roles providing direct care (Hussein 2009).

Ageist erotophobia: self-governance

It became clear early during fieldwork that a major barrier to researching and thus addressing sexuality and intimacy appears in a form of thinking that locates care home residents outside/beyond sexual citizenship. Such thought can be internalized by residents themselves in ways that govern and constrain their thought, action and self-identity as non-sexual citizens. When asked what he thought sexuality meant to residents, William (aged 78) replied:

Negative... Nobody talks about it... Nobody practices it. We just live as we are... We've had our sex life way back... We've had our time; we are a dying breed... I think yer wastin' yer bloody time. I think you should leave it [the subject] alone. It's people's personal life... Have you had a look around at some of these? They're that bloody old, they've got cobwebs on 'em.

William's view that 'nobody talks about' or 'practices' sexual activity indicated how ageist erotophobia is implicated in panoptical silencing of sexuality (and intimacy) among residents, staff and relatives (Hafford-Letchfield 2008, Bauer *et al.* 2012). By 'panoptical', we refer to discourse that constructs residents as postsexual, even postintimate that becomes internalized unconsciously as part of unwritten rules of the environment. Indeed, Villar *et al.* (2015) discovered that a significant minority of staff and residents considered even marital heterosexual sex unacceptable in care homes for older people. William's assumptions indicate the workings of an ageist erotophobia that could prevent older people being imagined as sexual beings and could involve a visceral sense of disgust at such a thought. We get a sense of this in William's words that characterize residents as synonymous with decline, decrepitude and death – the very opposite of sexual vitality or generativity. This is symbolized in his reference to 'cobwebs'. Even when asked whether his view was a particular one among a range of possibilities, William was adamant that his statement applied universally and that all residents were distinctly postsexual. The discursive exclusion of intimacy was also recognized by spouse, Olivia, (aged 60) who spoke of how environmental arrangements designed out possibilities for intimacy given the lack of a double bed in her husband's room and the lack of double rooms. The same process was recognized by a female care home worker in FG2 who spoke of how displays of affection between residents could attract censure from staff and residents (Villar *et al.* 2015).

Moreover, reservations, rather than outright opposition, concerning the value of the research could be expressed in terms of practical consideration such as the age-group of residents:

I think you've got to look at the age factor. ...this [research] is geared up for people a lot older than us because we're in our sixties and there's very few in their sixties here. You're looking at 80 plus... I don't think it's really worth the while. [Later] ...I think you'll find it very difficult to get people to open up to you. (Olivia, spouse, interviewed with husband, John, resident, aged 61).

While age is presented as a practical impediment to the proposed research, the above response indicates how ageist

erotophobic discourse engenders difficulty imagining the oldest in society as sexual beings. For Olivia, the research could be frustrated by a generational reluctance to 'open up' on a sensitive subject. Indeed, such concerns were echoed by spousal interviewee (Marjorie, aged between 50 and 65). Furthermore, Olivia and John considered that our proposed research would be more appropriate to and should thus be targeted at, residents of their generation (e.g. the younger old needing care). While we should heed participants' views about the personal, sensitive nature of our study, the stories below suggest that it would be unethical to exclude older or the oldest residents from any study.

Resisting ageist erotophobia

Although the idea of residents as post-sexual was commonly invoked by residents, spouses and staff, there emerged alternative views on the legitimacy and value of researching (and addressing) sexuality and intimacy:

Female researcher: Do you think they'd be shocked though if a carer said, 'And what about your sex life?'

Emily, resident: No, I think they [residents] would realize that they [staff] were trying to help them. Some people make a big fuss of it, others don't.

Although Emily was hardly full of enthusiasm, nevertheless, she accepts even that research (and arrangements) concerning sex and intimacy would largely be welcomed by residents rather than be seen as intrinsically offensive if not taboo. Sexual citizenship was not completely written off in her account, which acknowledged a spectrum of responses (perhaps shaped by biographical difference). These range from making 'a fuss' (or an issue) of wanting to continue with sexual experience to responses reflecting indifference to sex. Further, Emily's words recognize adult autonomy, (given opportunities and freedom from restrictions) and mark limits to erotophobic self-control animated by ageism and challenge to stereotypes of prudishness. However, later in the interview, Emily framed intimacy as being largely contingent on and legitimated by being part of 'a couple', whether heterosexual or homosexual; thinking as reflected in Cronin's (2015) exploration of how heterosexuals 'do' coupling.

Given care staff's encounters with everyday dilemmas, including sexualized ones and their need to have regard to myriad legal, ethical, institutional and service user requirements, it was unsurprising that they more clearly expressed enthusiasm about the research than residents. For example, one manager (female FG1) explained: '...when we spoke to

Paul (Principal Investigator), we were just delighted to know that research is taking place because it tends to be... “Forget about that and ignore it.” Such comments indicate that our research was welcomed for its potential to produce answers to long-held concerns. They also reflected various grey areas of consent and over-cautious approaches to safeguarding welfare. Besides, care staff’s positioning also afforded them opportunities to make practical recommendations that challenged ageist erotophobia. One female care worker (FG1) considered that ‘older people probably would be very open, maybe among themselves and their own peer group to talking about it... (sexuality)’ Indeed, this recognition is suggestive of peer education, which could contribute to empowering residents as sexual citizens and thus help them resist infantilization and pressures towards erotophobic self-governance.

Strategy, inclusivity and sensitivity in research on sexuality and intimacy

As intimated just above, care staff were in a position to articulate recommendations concerning how to go about researching sexuality and intimacy. These recommendations largely concerned the necessity and value of including residents in any research. First, as highlighted by a female manager (FG1) when setting up the focus group session, researchers could encounter difficulties in recruiting a sample given that nursing homes in particular are unlikely to have many residents with sufficient and demonstrable capacity to consent. This was echoed by a female carer (FG2) who declared: ‘...it’s probably getting the right people to do it [participate]... So, you are going to have to look more widely’. Such statements implicitly recognize that any research would draw from a restricted population and thus require pragmatic and purposive (strategic) sampling methods across a range of homes.

It was also significant that both focus groups concluded that the views and experiences of residents with a dementia should not be excluded from any research, though this was hedged by provisos. One care worker (female, 5 FG2) opined:

It would depend on days wouldn’t it? Because people with dementia, their capacity fluctuates different days. So, it would have to be coming in on a day which is a good for them... You might have to come back on another day when they were ready.

Both groups were clear that the research should only include residents in the earlier stages of a dementia with sufficient and demonstrable capacity to consent. Any research on sexuality and intimacy would then need to take account of the demographics and composition of this sub-sector of care, which includes: nursing homes; residential

homes, mixed nursing and residential homes; and facilities where provision for older citizens is part of residential provision for severely disabled people.

However, residents and one spouse were not without their views on how to conduct our proposed research:

Male interviewer: ...do you think there might be things that we should avoid asking?

Olivia (spouse interviewed with resident husband, John): I’d like to see a bit more information. That might be handy. Basically... we didn’t know really what you wanted to know and we didn’t know how far you were going delve.

In the above exchange, Olivia highlights the kind of anxieties that can happen when prospective participants are provided with only partial information about the *kind of* questions likely to be asked. Olivia’s words underscore the importance of well thought-out communication prior to any research encounter, which could risk discouraging participation. It appears that the participant information sheet (PIS), which emphasized that we would be asking for subjects’ views on the principle of investigating sexuality and intimacy and despite our explicit request, had not been passed onto the participant by care home staff. This is not a criticism of staff (who have manifold concerns to deal with) but rather highlights the need for the interviewer to go through the PIS with participants just before interview to check on understanding. This was actually carried out as a matter of procedure and, in one case, resulted in the withdrawal of one female resident (CH2) prior to interview.

Moreover, it was significant that Olivia drew on commonly available discourse of sexuality as: ‘... a very private thing... I don’t want anybody to know what I did or did not do’. The intrinsically private nature of sexual and intimate acts motivated Olivia and John, to recommend an approach to researching sexuality in the context of care homes that addresses individual needs, but avoids questioning about sexual tastes or histories. This explains why they welcomed the use of images and vignettes during interview; a view supported by both focus groups who considered the use of vignettes acted as an ‘ice-breaker’ that would help minimize or avoid over-disclosure.

Limitations

The sample size and regional focus impose limitations on the strength of claims we can make. Conspicuous by their absence in our research were the accounts of LGB&T and non-white individuals. Given the relative neglect of the issues discussed in this article, further research on a

national (and even cross-national) basis needs to be done. Although not properly addressed in this article given the limited sample, failure to address sexuality and intimacy can have serious implications, especially concerning the mental health of LGB&T residents who have struggled over years to establish an identity (Willis *et al.* 2013). Such thinking underscores study participants' view and our own belief that any study needs to be based on a purposive sample that includes key dimensions of variation. Indeed, considerations of sexuality (regardless of whether residents identify as gay, straight or bisexual etc) seem to represent the missing parts of the holistic care jigsaw for residents.

Conclusion

This article has explored themes in consultative research with key stakeholders on the feasibility/desirability of investigating sexuality and intimacy in care homes accommodating older people. The variety of accounts of responses towards researching sexuality and intimacy could be instructive for academics and practitioners in other countries. Reservations, which emerged in resident and spousal interviews ranged from objection on moral grounds to practical concerns about the relevance of the research to the oldest citizens. Such responses are indicative of ageist erotophobia that encourages the assumption of residents (if not older people) as postsexual and exclusion from the sexual and intimate imaginary.

However, acceptance of the research, especially among professional carers, indicated a more general acceptance of the principle of our proposed research *and* challenges to ageist erotophobia. Study participants made three recommendations for researchers concerning the need to:

- sample as purposively and widely as possible given the nature of the population/compromised capacity to consent;
- avoid excluding from any study, individuals in the early stages of dementia but to have regard to their fluctuating capacities;
- ensure that communication with (prospective) participants properly addresses informed consent and that researchers exercise care when addressing questions that could relate to sexual histories/preferences. Researchers may need to balance framing of questions with the need for free-flowing dialogue.

Finally, our study has research, policy and practice ramifications. As already noted, future studies should factor in differences of ethnicity and sexuality (which can intersect). By implication, the study highlights the need for properly

funded care that transcends bed-and-body approaches and for implementation of official and institutional guidance concerning training and other staff development measures designed to provide holistic care that embraces sex, sexuality and intimacy (Authors, year). Such matters need addressing as matter of urgency or we risk older compromising residents' well-being and infringing choices and rights.

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Conflict of interest

No conflict of interest has been declared by the authors.

Author contributions

All authors contributed to the conception of the project and design of instruments. Authors 1, 3, 4 and 5 conducted the fieldwork. All authors contributed to interpretation of the data. Author 1 drafted the article assisted by author 2, which involved integrating substantial commentary and revisions from authors 3, 4 and 5. All authors have agreed on the final version and meet at least one of the following criteria [recommended by the ICMJE (http://www.icmje.org/ethical_1author.html)]:

- substantial contributions to conception and design, acquisition of data or analysis and interpretation of data;
- drafting the article or revising it critically for important intellectual content.

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